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ABSTRACT

This symposium report is designed to provide guidance about major conceptual and methodological issues in research relating to families whose children have emotional, behavioral, or mental disorders. Participants in the symposium identified historical themes, dominant constructs, methodological issues, and recent developments related to family research in children's mental health. Four research areas for further development were then identified, and each research area was assigned to a work group, which defined the area and identified further research issues. The four areas were: parent-professional collaborations and training systems; family support and family advocacy; multicultural competence; and financing of family support and family-centered services. Participants then generated recommendations regarding conceptual and material support needed to advance the research agenda. Appendixes contain a list of participants; outlines of presentations by Joan Patterson and George Singer; a list of family research themes and topics; and a list of eight references and resources. (JDD)

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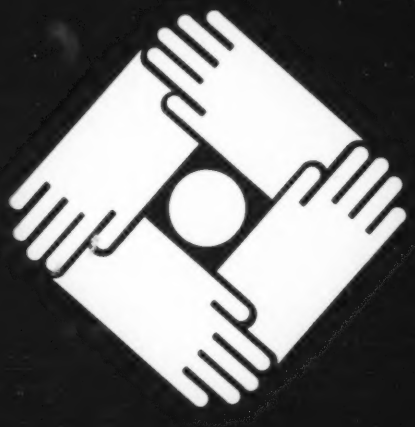
FAMILY RESEARCH AND DEMONSTRATION SYMPOSIUM REPORT



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FAMILY RESEARCH AND DEMONSTRATION SYMPOSIUM REPORT

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I. INTRODUCTION

In less than a decade we have witnessed perceptible changes in theories, beliefs, and practices regarding appropriate roles and services for families whose children have serious emotional, behavioral, or mental disorders. Stimulated in part by programs supported by the Child and Adolescent Service System Program (CASSP) formerly of the National Institute of Mental Health, now in the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), these changes represent an overall movement toward community-based, family-centered services and family participation in all aspects of the planning, implementation, and evaluation of services. In particular, there is renewed interest in preserving families, increased understanding that families need resources and support in order to deal with their difficult children at home, and a growing appreciation of the positive contribution that families can make to improving services and shaping public policy. These changes also parallel changes in other fields, notably adult mental health, developmental disabilities, and chronic childhood illness and disability.

As is often true, research priorities and actual research endeavors regarding family issues in children's mental health have not kept pace with changing concepts and practices in the field. Although a few current studies are focused on children's mental health issues from a family perspective, until now, there has been no systematic examination of current and future research issues in this area.

To address this gap, a small working meeting was held in Arlington, Virginia on November 22-24, 1992. Participants in the *Family Symposium: Developing a Research and Demonstration Agenda for Services in Children's Mental Health* represented a wide variety of perspectives, including researchers, service providers, family members, and research funding sources (see Appendix A for a list of participants). The meeting was organized by the Research and Training Center on Family Support and Children's Mental Health, Portland State University, and sponsored by the Research and Training Center in collaboration with the Child, Adolescent and Family Branch, Center for Mental Health Services, SAMHSA, U.S. Department of Health and Human Services.

The purposes of the *Family Symposium* were:

1. To identify the current state of knowledge regarding family issues in children's mental health, both in terms of content and method, and to suggest future directions.

2. To develop recommendations about promising areas of investigation in family research in children's mental health.

3. To identify ways to encourage investigation in the area of family-related research, to stimulate support for this area of investigation, and to promote dissemination of research efforts and results.

For this meeting a working definition of family research was prepared:

> Research by, for, and with families whose children and adolescents have serious emotional disorders. Focus is on applied research involving the interaction of three domains, or on related issues within each of the three: (1) the behaviors and needs of the child or adolescent; (2) the behaviors and needs of the whole family in response to or interaction with the child's needs and behaviors, and; (3) the availability to the child and family of needed resources and supports, both formal and informal.

The working session began with presentations about the historical roots, dominant constructs, and research approaches that have characterized family research in other fields. Joan Patterson, Ph.D., presented information about family research in the area of chronic childhood illness or disability, and family research issues in the field of developmental disabilities were addressed by George Singer, Ph.D. Outlines of these presentations are contained in Appendix B.

Following the format used by Drs. Patterson and Singer, meeting participants generated information about the historical roots, dominant ideas, and research approaches and methodological issues in family research in children's mental health. This activity provided participants with a common foundation of information on which to build their work during the *Family Symposium*. The results of these deliberations are summarized in Section II, entitled **Family Research in Children's Mental Health**, page 3.

Participants also contributed ideas about family research topics that they thought should be given attention in the future; they then participated in a priority-setting process to identify research areas for further development during the work sessions. The four areas selected were:

1. Professionals and systems: Parent-professional collaborations and training systems;
2. Family support and family advocacy;
3. Multicultural competence, and;
4. Financing of family support and family-centered services.

Each of the four research areas was assigned to one of four work groups. Work group members addressed their attention to further defining each research area, identifying research issues or questions, and identifying issues of research method for each topical area. Section III, entitled **Building a Research Agenda**, contains the results of each group's efforts.

After the findings and recommendations of each work group were presented to a general session, participants generated recommendations regarding conceptual and material support needed to advance the family research agenda in children's mental health. The recommendations related to this activity are presented in Section IV, entitled **Promoting Family Research and Demonstrations: Recommendations and Resources.**

Family research in children's mental health services is a developing field that presents many exciting challenges and opportunities. We hope that these proceedings will stimulate researchers, family members, service providers and others to become involved in research related to their interests and concerns about services for families whose children have emotional, behavioral, or mental disorders. This document is designed to provide some guidance about major conceptual and methodological issues in family research, and to identify useful resources.

II. FAMILY RESEARCH IN CHILDREN'S MENTAL HEALTH

Members of the *Family Symposium* identified the following historical themes, dominant constructs, methodological issues, and recent developments related to family research in children's mental health:

A. History and Dominant Constructs

I. Assumptions about etiology of childhood mental disorders that focused on parent-child, other family interactions as primarily responsible for faulty development or pathology shaped practice, preferences for interventions, i.e.:

- use of primarily psychological and some medical (drug) interventions;
- acceptance, and in some cases, encouragement of out-of-home placements such as residential treatment and foster care;
- focus primarily on treatment of child, treatment of parents or family aimed at improving functioning of child;
- little/no attention to family support, other needs of family members.
- emphasis on diagnostic categories with regard to eligibility for services, as well as for purposes of planning treatment.

II. Concepts about the etiology of childhood disorders also shaped the direction of research about families in children's mental health:

- focus on identifying family characteristics, patterns and practices related to child's behaviors, emotions, or other problems;
- interest in families mainly as context for child's problems or development;
- little attention to needs, preferences, perceptions of family members, although there has been some work on consumer satisfaction.

III. Outcomes of interest in children's mental health tended to be variables of interest to clinicians, policy-makers, not necessarily those of families and children

- e.g., cost, child and family functioning, child and family well-being;
- little focus on needs, preferences, experiences of families.

B. Recent Developments

I. Recent shifts in knowledge, theory, philosophy related to a variety of factors:

- increased knowledge about etiology has led to a shift from primarily psychological models to more complex bio-psycho-social explanations of childhood emotional, behavioral and mental disorders.

- shift from a unidirectional focus on the effects of family functioning/dysfunctioning on child behavior to recognition of the transactional nature of intrafamilial relationships;

- recognition of outside influences on family behavior, ecological approaches (child-in, family-in community);

- better information about life course of childhood disorders has increased recognition of complexity, persistence of problems, hence recognition of the need for long-term planning for some children with the most serious problems;

- increased consumerism, involvement of parents and other family members has led to rejection of pathologizing, blaming families, call for new partnership;

- emphasis on community-based service has led to recognition of need of all families (birth, adoptive, foster) for tangible and emotional support.

II. These changes have led to call for services that:

- are community-based;

- are comprehensive, individualized, i.e., responsive to whole range of needs, not just therapeutic considerations and flexible;

- are child and family-focused, with emphasis on keeping children in their own homes whenever possible;

- are responsive to needs of whole family, not just the identified child;

- employ a variety of interventions and strategies, i.e., educational, psychoeducational, rehabilitative;

- are coordinated, including mechanisms for inter-agency coordination at both the systems, and individual case level;

- promote partnerships between children, families, and professional service providers;

- promote culturally appropriate, accessible, and acceptable services for diverse populations of children and families (racial, cultural, ethnic, geographic, class differences, among others); and

- acknowledge and build on family strengths.

III. Changes in service system are beginning to be accompanied by shifts in research priorities and approaches:

- increased interest in family perspective, needs, including some focus on "family burden," a concept borrowed from adult mental health;

- expanded roles for families in research process, recognition that family members can make positive contribution to the entire research process, from identification of priorities, development of measures, and data collection to interpretation of results and dissemination of findings;

- increased interest in research and evaluation that helps to discover best approaches to developing community-based, family-centered system;

- investigations of relationships between families, and professional service providers, starting with documenting differences in perspectives, use of self-efficacy theory and intervention to enhance family empowerment;

- evaluation of approaches designed to assure culturally appropriate services; and

- focus on family empowerment as a goal.

IV. Methodological Issues

1. Lack of comprehensive theory; focus on micro issues.

2. Developmental nature of child behavior, family context.

3. Multiple problems/needs of children and families require comprehensive views, approaches; need to overcome past fragmentation and include lessons from fields of mental health, developmental disability, social welfare, juvenile justice, etc.

4. Lack of appropriate instrumentation; there is a need for better instrumentation to examine family issues, relationships and functioning over time.

5. Need to link research to services issues.

6. Need to integrate public health/social welfare approaches.

7. Unit of analysis has tended to be mothers as objects of study or informants, mostly white, middle-class; studying family as unit of analysis is complex.

8. Analytic issues:

   a. Interesting developments in longitudinal research modeling growth in family functioning;

   b. Services research is in early stages of development; we need to integrate service utilization and outcomes; and

   c. Need multi-method, multiple sources of information.

9. Need strategies to increase the scientific rigor of studies when random assignment is not used.

10. Need improved methods for assessing system changes.

11. Need more precise definition and measurement of independent variables, e.g., family support, individualized services, advocacy, etc.

12. Need better sampling strategies; samples in the past have been small and have tended to lack diversity.

13. Need multiple perspectives on outcome, i.e., family members, service providers, administrators, policy-makers.

14. Need to provide feed back of research findings to participants.

III. BUILDING A RESEARCH AND DEMONSTRATION AGENDA

A. Themes and Concepts that Received Votes

From the extensive list of themes and concepts generated by the full group of research symposium participants, a list or priority areas was identified by an individual voting process. The process was as follows: All themes and concepts were arrayed on flipchart sheets that were posted on walls of the meeting room. Each participant received four colored dots and was asked to place a dot next to those themes or concepts that he or she considered to be of especially high priority. These "votes" were then tallied. The themes and concepts receiving the most votes were the following:

- Studies on biculturalism/or multicultural competence. (7 votes)
- Studies to learn more about how families define "quality of life" and "competence" in children. (3 votes)
- Families should participate in measurement development efforts. (1 vote)
- Studies of what factors determine various children's pathways into different service systems, i.e., juvenile justice, mental health, child welfare, etc. (1 vote)
- Research that studies families within the context of the communities and systems in which they live (including natural helping context of community). (3 votes)
- Caregiving families with special needs: (families with AIDS, adoptive families, substance abuse). (2 votes)
- Research on abuse and neglect. (1 vote)
- Research on other services besides therapy, e.g., respite, psycho-education, prevention. (5 votes)
- Conducting research on school system, child welfare, mental health, judicial -- with as much rigor as we study family systems. (4 votes)
- Use of informal versus formal services by families. (2 votes)
- Use of research knowledge to inform/influence curricula of schools training professionals. (5 votes)
- Study of racism as DSM-III category (parallel to a delusional disorder). (3 votes)
- How to better provide services to populations that do not access existing services. (3 votes)
- Study of outcomes - clinical/researcher, consumer, societal (i.e., cost effectiveness), cost vs. benefit. (2 votes)
- Building parent-professional collaboration in services and research. (4 votes)
- The effectiveness of "family support movement" on services. (4 votes)

- Financing of community-based, family-centered, flexible services/supports. (10 votes)

Through group discussion and consensus, these priority themes and concepts were grouped and reorganized into four main areas to be further discussed and developed by work groups. The four areas were:

1. Professionals and systems: parent-professional collaboration, training, and systems change;

2. Family support and family advocacy;

3. Multicultural competence: and,

4. Financing.

The following reports describe the results of these work groups.

B. REPORTS FROM WORKGROUPS

Research Theme: Research on Professionals and Systems; Parent-Professional Collaboration, Professional Training, and Systems Change

Group 1:
Paul Koren (facilitator)
Abram Rosenblatt (recorder)
Judy Katz-Leavy
May Kwan Lorenzo
Joan Patterson

The first work group focused on the area of formal services and systems. Special emphasis was given to how such services and systems affect and, in turn, are affected by families and informal or natural supports that might be present in families' lives. Also included here was the general issue of how professionals approach working with families and how this approach might be enhanced or improved by training.

I. IN DEFINING THIS RESEARCH AREA, THE FOLLOWING IDEAS WERE SUGGESTED:

1. A comprehensive focus on formal systems should take into account influences from natural systems, informal systems, and mixes between the two.

2. One important approach to examining the family-centered qualities of formal systems is to study the degree of parent-professional collaboration that occurs in the process of service delivery.

3. One important means of changing formal systems is through training of professionals at all levels and disciplines using CASSP principles and emphasizing: (1) collaboration among professionals in the context of a service delivery team; (2) the incorporation of cultural diversity within service delivery approaches; (3) coordination of services among different child-serving organizations; and (4) attitude change among professionals.

4. An improvement in collaboration among professionals and organizations on behalf of children requires different levels of organizational and political support; that is, support for such concepts is needed at all administrative levels, not just the line staff level.

5. The systematic study of changes in formal services requires more attention to the development of appropriate measurement tools, particularly those that focus on outcomes, an incremental approach to the development of knowledge in this area, and adequate attention to evaluation of innovative programs.

6. In developing innovative demonstration projects, more attention should be directed toward examining the effects of the tension occasioned by the disadvantages of categorical service delivery and the pragmatic need to target specific problems.

7. In examining the formal system, the area of public-private system coordination needs more attention as well as public intra-sector coordination.

II. SOME SUGGESTED RESEARCH QUESTIONS:

1. What changes occur in private systems of care when changes are made in the public systems? What creative partnerships between public and private systems can be developed such as a shared risk pool?

2. What professional characteristics, family characteristics and organizational characteristics promote and facilitate parent-professional collaboration?

3. How can we train professionals to be collaborative (family-professional),team oriented (professional-professional), and respectful of cultural diversity (culturally competent)?

4. What are reliable and valid measures that reflect CASSP or other innovative principles -- both outcomes and process and in terms of the child, family, professional and system levels?

5. What facilitates and impedes system development and change? What is the role of research in this process? What are the roles of consumers, advocates, practitioners, professionals, and other stakeholders in this process?

6. What financing strategies and organizational change strategies promote integrated service delivery?

7. What can be learned about the entrance to and pathways through different services systems for different ethnic and cultural groups?

8. How can formal systems better utilize the expertise of indigenous workers and other community members?

III. METHOD ISSUES

The following methodological issues were identified as particularly worthy of attention:

1. Better outcome and process measures are needed.

2. Research designs that blend qualitative and quantitative methods are appropriate given the state of research in this area.

3. Experimental methods, while preferable for scientific rigor, are sometimes impractical given natural impediments to adequate control of the field research environment. Quasi- and non-experimental designs may provide valuable information, given the state of knowledge in this area, and should be considered.

4. Longitudinal research is especially valuable given the context of child development and should be encouraged.

5. Systems and policy oriented methods of research should be encouraged.

6. Explicit attention needs to be given to the issues of cultural bias and diversity in current measures and methods.

7. Sampling needs to be representative of ethnic and cultural minorities.

Comments: While recent progress has been made in improving and expanding formal services for children with severe emotional disorders, there is still a considerable need for new service development. Research has a strong role to play in this development, provided that such research is pragmatic in focus, credible to the involved communities, and grounded in the concerns and needs of families. To the extent possible, participation of families in the research process is one way of addressing some of these issues. Increased attention to measurement and methodological issues is also especially warranted, since research findings must be credible to scientific and governmental bodies if such findings are to be translated into system improvements. Given the pivotal nature of children's mental health services in addressing current social needs and well as future ones, research on systems of care deserves to be given strong priority in new funding initiatives.

Research Theme: Research on Family Support and Family Advocacy

Group 2:

Nancy Koroloff (facilitator)
Naomi Karp (recorder)
Creasa Reed
George Singer
Steve Lopez

This group focused on the areas of family support services and family advocacy activities. Special emphasis was given to discussing the definition of family support and how that definition might effect the research that is done. For the group's discussion we agreed to define family support as "whatever that family says it needs to maintain its family member with special needs at home."

I. IN DEFINING THIS RESEARCH AREA, THE FOLLOWING IDEAS WERE SUGGESTED:

1. Clarification of financing issues related to family support is critical. Questions need to be asked about how methods of finance effect the family support services offered, what are the systems' costs for family support, how flexible funding streams and mechanisms can be used.

2. Family viewpoint must be incorporated into all research regarding family support. Research needs to examine what families want, what they will use, how financing effects families' use of services.

3. Research into the impact of family members participation at all levels is rare. Research needs to investigate the impact of parent involvement at the case planning level, the service delivery level and the policy or system change level. Research needs to be designed that explores the effect of advocacy activities on the individual parent advocate.

4. A major research need is the examination of the outcomes of family support. What is the impact of family support services on the child, family, service system, society? Outcomes of family support need to be defined across multiple perspectives and settings. Input needs to come from researchers, family members and policy makers.

II. SOME SUGGESTED RESEARCH QUESTIONS:

Natural family support networks

1. How do families get support when there are no services and supports available to them?

2. How do informal networks form and stabilize?

3. What role do cultural differences play in the development and use of formal and informal support?

4. What is the difference between professionally-run support groups vs family-run support groups?

Families' choices in using supports and services

5. What services do families choose and why? Which families prefer which family support services?

6. How do we provide family support for those families whose children are not yet in the "system," not in the mental health system, who have dropped out of the "system"?

7. How does a cash subsidy program impact families? (Need a national study across states).

8. Does the availability of family support services reduce the incidence of child abuse?

9. What are the benefits of family support services in general? What are the benefits of family support on siblings?

10. What conditions encourage family-professional collaboration and family support?

Family members as systems change advocates

11. What are the characteristics of family members who become effective systems advocates?

12. What roles can professionals play in identifying and nurturing family members as system advocates?

13. What difference does family member involvement make in the system change process?

14. What conditions support family advocacy?

Financing issues

15. How can institutional dollars be moved with children to support them and their families in the community?

16. What is the impact of increased family support services on the traditional service delivery system? What happens to employment opportunities? How are support funds used?

17. How do Medicaid and private insurance plans differ in their reimbursement for family support services? How do they differ in terms of quality of care and access to services?

18. What is the effect of combining family support funds for separate disabilities at the state level? (In some states, other disabilities that have been successful in obtaining family support services do not want families of children with emotional disabilities attached to their funds. Fear is that adding a disability will make less available to all.)

Stigma

19. Does family support help reduce stigma?

20. How can schools reduce the stigma associated with a label of SED, etc? Do separate services increase stigma?

21. How do medications, therapies, etc. impact on the child's development and social relationships?

22. How can diversity be valued, respected, and celebrated across settings and groups?

III. METHOD ISSUES:

The following methodological issues were identified as particularly important to quality research in the area of family support and family advocacy.

1. Careful attention needs to be given to the definition of family support services; clarification of the relationship between terms "family support" and "wrap-around services;" definition of "successfully coping family."

2. Researchers need to explore potential theoretical models, research should be based on theoretical frameworks when possible. Research into stigma is an example of where this is possible.

3. Research designs need to employ both qualitative and quantitative methods. Much research in this area needs a qualitative element.

4. Research plans need to allow for explicating the intervention carefully. Use both descriptive and definitional techniques.

5. More effort needs to go into developing measures that are strength-based and non-intrusive.

6. Involve family members and children/youth in all phases of the research process. Special effort needs to be made to involve family members and consumers in the design of research and evaluation.

7. Dissemination of results to families, children, service providers is critical. Need more work regarding most effective methods of dissemination.

8. Families and consumers need adequate compensation for taking part in design, implementation and evaluation of research.

9. Need more observational research in some of these areas, funders need to support this type of research.

Comments: Interest in questions related to family support and family member advocacy is very recent in the field of children's mental health. Therefore it is critical that funding be made available to studies that are more exploratory in nature allowing for the development of appropriate frameworks, definitions and measures. Researchers interested in this need to be alert to research that has been done in other fields, i.e., research done with families who caregivers for persons with mental retardation or developmental disabilities. Research in the areas of family support and family advocacy will be value based to some extent. These value orientations need to be clearly explicated as underlying assumptions of the research.

Research Theme: Research on Multicultural Competence

Group 3:

Barbara Friesen (facilitator)
Mary Evans (recorder)
Marva Benjamin
Carol Howe
Diane Sondheimer

This work group focused on issues related to the needs, preferences, and experiences of the diverse population of children and families who need mental health services.

I. IN DEFINING THIS RESEARCH AREA, THE FOLLOWING IDEAS WERE SUGGESTED:

While some group members pointed out that the notion of culture applies to all people, and includes diversity related to variables such as geography, religion, and social class, the group primarily focused on issues related to children and families of color.

The research area includes both issues primarily related to the system and concerns that are more clinical, or centered at the level of the child and family. For example, there was interest in developing and assessing strategies for reducing community violence and providing alternatives to violence (system level) as well as treating individuals who have been exposed to violence (child and family level). Group members noted that cultural issues should cut across all other topics under consideration at this meeting.

II. SOME SUGGESTED RESEARCH AREAS:

Systems-level issues:

- over-representation of children of color in special education, juvenile justice and child welfare programs;
- problems of access and barriers to service;
- community and family violence; and
- approaches to training professionals to competently work face-to-face with persons from other cultural groups.

Child and family-level topics:

- What are the cultural variables important to family coping and adaptability?;
- What are the impacts of racism and discrimination on the mental health of children and families?;
- What child-rearing practices facilitate adjustment to minority/majority cultures?;

- What constitutes culturally competent psychological, biological, social assessments of children of color? In the development and norming of measures used for assessment, it is important that the new measures be related to existing ones.

The work group also noted the work of a Research and Evaluation Symposium on Minority Issues sponsored by the Georgetown CASSP Technical Assistance Center in January 1992. Issues identified by a work group on minority family issues included the following points:

- The definition of family is very important, and should be defined by the clients themselves;
- There is a critical need to identify families that are functioning well and learn from them;
- Research attention should be given to identifying the mechanisms through which elders lose their influence over younger generations;
- We need to acknowledge and explore gender differences in different ethnic groups;
- Economic factors and use of resources in dealing with larger service deliver systems should be taken into account;
- There is a need for research on life cycle and child developmental stages among diverse ethnic and cultural groups;
- Research demonstrations that teach children how to handle racism are needed;
- Language issues must be taken into account in mental health services research; and
- There is a need for more case studies and ethnographic studies to complement the traditional research conducted.

The group identified two topics for further elaboration:

Child-rearing practices facilitative of children living in a bi-cultural world:

1. Identify positive adaptive strategies used by families.
2. Compare "more successful" child-rearing practices with those that appear to be less successful re: preparing children to live in multicultural world.
3. Identify the factors, especially environmental or support factors, that are associated with successful outcomes for children and families (e.g., income, education, supportive family, etc.).
4. Conduct research demonstration using families who are comfortable with their culture as trainer/support for other families.

Over-representation of children of color in deep-end services:

1. Evaluate model service alternatives;

2. Provide technical assistance and resources to model programs to develop evaluations to produce good outcome data;

3. Need resources to replicate model programs and carefully evaluate replications; and

4. Work to translate effective programs across cultural boundaries; need to get families involved in this effort.

III. METHOD ISSUES

The following issues were identified as particularly important in the area of cultural competence in service to children with emotional disorders and their families:

1. Developing culturally competent research processes raises issues about who should develop theories and program; need to involve in research families and researchers who represent population(s) being studied. The group noted that we need more researchers of color (fewer than three percent of persons receiving National Institutes of Health grants are researchers of color).

2. Suggest using a community panel to define outcomes of interest for research projects.

3. Need to develop strategies to assure that relevant comparison groups are included in research.

4. Data collectors and respondents must be appropriately matched (bi-cultural).

5. We need to develop mechanisms to share translations of existing instruments, so that precious resources are not wasted.

6. In addition to translations into various languages, research materials should be accessible to people with communication-related disabilities such as hearing or sight-impairments.

Comments: Members of the work group commented that this important research area needed more time to fully develop, and agreed to include some of the work done by the Georgetown Child and Adolescent Service Systems Program Technical Assistance Center earlier in 1992. All studies that are proposed should take cultural issues into account. In addition, there is a need for much focused research in this area. There is also a need for systems change to produce more support for culturally diverse service providers and researchers. It was suggested that researchers working in this area need to link more closely with the Minority Research Centers funded by the National Institute of Mental Health.

Research Theme: Research on Financing Family Support Options and Services

Group 4:
Harold Briggs (facilitator)
Al Duchnowski (recorder)
Tom McDonald
Betsey Thomas-Train
Craig Ann Heflinger

The fourth work group focused on the area of financing for family support options and services. Although the theme was financing, the group agreed that a clear description of family support as a variable needs to be accomplished before financing studies can be done.

I. IN DEFINING THIS RESEARCH AREA, THE FOLLOWING QUESTIONS WERE SUGGESTED:

1. Which families are we talking about -- e.g., child welfare, special education? This is more than mental health, this is the old problem of multi-problem and multi-agency.

2. What outcomes are we interested in for supporting families -- e.g., reduced use of out-of-home placement an outcome? Is the outcome higher achievement? Is the outcome fewer criminal justice incidents? Better child and family functioning? Increased life satisfaction? Is one of the outcomes enhanced economic self-sufficiency?

3. Are we financing for better services or better outcomes?

4. Are long term savings expected from funding family support? What are the cost savings -- longitudinal and short term?

5. Do families with children in out-of-home placement need family support and will it lead to better outcomes?

6. What are the issues related to needed family support services that are related to children with different diagnosis and problems?

7. How can inequities in local service areas be addressed? Should financing mechanisms include redistribution of resources?

II. SOME SUGGESTED RESEARCH TOPICS:

1. What is the financing history of current family support programs in children's mental health and other fields? What have we seen? What has changed? What have been the previous financing patterns?

2. What are the current costs of family support services? Who pays for service delivery? What is being spent by public and private domains? What is being spent on children by diagnosis over time? What is being spent on different groups? How are different communities funded?

3. What are the costs of alternative models -- e.g., compare the costs of professionally-driven and family-driven systems?

4. What models are most likely to promote local control and autonomy? Comparative studies of various approaches are needed, e.g., interorganizational approaches vs. categorical funding?

5. What is the effectiveness and efficiency of various methods of distributing and providing access to resources, e.g., the use of vouchers for funding services?

6. What are the implementation issues that impede or enhance delivery of alternative models?

7. What are the relative costs of volunteer versus paid family support services?

8. What incentives exist or can be developed for funding in-family support services?

9. What are the cost-benefits and what is the cost-effectiveness of providing family support services? We need comparative studies, i.e., the true costs of providing family support compared to the costs for not.

Comment: All studies of services in child mental health should include analysis of costs.

III. METHOD ISSUES

1. Defining family support as an independent variable.

2. Defining family support outcomes.

3. Developing strategies for assigning dollars to costs and benefits.

4. There are no economic models for children's mental health services. How can they be transferred from other fields?

5. Attracting researchers to this area.

6. Attracting economists to the children's mental health field.

7. Overcoming the barriers to sharing information across agencies, e.g., confidentiality and matching records.

8. Overcoming different definitions of family support in different agencies.

9. Difficulty of using experimental designs; how to build the strongest possible design.

10. Identifying families and children to be studied.

11. What constitutes full informed consent in this area?

12. Should findings be shared with families?

13. How can family members be trained in the research process?

14. There is a need for exploratory work in this area. How can funding be obtained?

Recent progress in recognition that families who are caring for children with severe mental and emotional problems need support has not been matched by funding for these services. There is a great need for research to carefully track the benefits and costs of family support services (both formal and informal). Greater attention needs to be paid to the true costs of the current system, e.g., the costs to individual families and to society when one parent must quit work to provide care and supervision for their child. There is also an urgent need to recruit qualified researchers and economists to this important area.

IV. PROMOTING FAMILY RESEARCH AND DEMONSTRATION: RECOMMENDATIONS AND RESOURCES

The last session of the Symposium was dedicated to examining future issues and strategies. After thinking about specific research areas, participants were asked to reflect on crosscutting aspects of designing, and implementing research projects and disseminating results. As a part of this session, representatives from the federal offices reviewed available funding programs and initiatives to increase participation in family oriented research. The following points were developed as a result of this discussion.

1. Take full advantage of current mechanisms for funding and for information sharing. Currently, the field initiated research proposals (NIDRR) and the R-18 and R-01 funding mechanisms (NIMH) are possibilities. The National Rehabilitation Information Center, the Mental Health Policy Research Center and the Resource Center on Cultural Competence (Maternal and Child Health) provide information retrieval systems that may be of use to researchers in the family area.

2. Even though some resources are available, there continues to be a demand for a way and/or a place to collect information and results from research on families. This place needs to be centralized and up-to-date, and make the best use of information technology.

3. Researchers interested in family research lack a way to get together to discuss findings and methodological issues. The Portland Research and Training Center will sponsor a national conference on family research in Spring 1994. There is a continued need for networking and information sharing among researchers.

4. Applied research on "lived day-by-day" issues of families will only occur with the continued and increased involvement of family members in the research process. Researchers must strive to work with families to define the important research issues. Periodic meetings and forums with family members need to be a part of all research designs. Family member involvement could be demonstrated in each proposal and might become a mandated criteria. There needs to be an ongoing effort to educate current researchers regarding family involvement in research. Publications that might help researchers are *Report of Consensus Conference on Principles of Family Research* sponsored by NIDRR and coordinated by the Beach Center, and *Guidelines for Family-Centered Research*, published by the Association for the Care of Children's Health. (See Appendix D). NIMH is currently doing a survey of family member involvement in research.

5. There is a continuing need to encourage/recruit researchers of color to the field of children's mental health and family research. Efforts such as the Technical Assistance Conference for researchers of color, sponsored by SAMHSA, need to be encouraged and increased. NIDRR funds partnerships between R&T Centers and historically black colleges.

6. The process of attracting new investigators to children's mental health and to family research is critical. Disincentives include the fact that there are limited non-grant positions that support researchers in this area, there are limited journal outlets, there is limited literature to build a research design on. Several new journals have

been introduced in the past two to three years to address this gap. (See Appendix D.) Stipends for graduate, post graduate work, may help to attract new investigators. Both NIDRR and NIMH have research fellowship programs. Call Dr. Joseph Fenton, (202) 205-9143 for current information on NIDRR Programs.

7. Specifically, there is a need to attract mental health economists to the children's mental health field. Cost effectiveness and cost benefit research needs to be encouraged and needs to be supported by the availability of knowledgeable economists for consultation.

8. Family members could be helpful in recruiting researchers with compatible values to the field of family research. Family members themselves are increasingly becoming researchers.

9. Program announcements that are family focused and require family involvement in designing research are encouraged. System change seems to happen through a combination of empathy and threat. A program announcement could ask for research on how best to accomplish system and attitudinal change.

10. It is recommended that funding sources and peer review committees acknowledge the value of exploratory research in this field (as opposed to research based on an experimental design). The lack of incentive for proposing research that is qualitative in nature should be recognized. Studies of macro issues, systems change and program implementation are often disqualified because they depend on qualitative methods.

11. Steps should be taken to encourage collaborative research across disability groups and across disciplines at the federal level. This may best be done through multiagency funding initiatives.

12. Continued attention needs to be given to diversity in all research. This includes diversity related to culture as well as disability. Costs of translation of instruments into languages other than English and into Braille could be shared among projects. Links with specialized organizations such as the Hispanic Center could support current research. Research projects could use existing groups of families of color to review research instruments and protocols.

13. Strength-oriented research should have priority. Studies of families who are coping well, or who cope well at certain times need to be encouraged. Examination of services within mainstream systems as well as specialized services for children with emotional disabilities need to receive equal attention. Instruments that assess both negative and positive aspects of caregiving must be developed and used.

APPENDIX A

FAMILY SYMPOSIUM:
DEVELOPING A RESEARCH AND DEMONSTRATION AGENDA
FOR SERVICES IN CHILDREN'S MENTAL HEALTH

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APPENDIX B

Research on Families of Children with Chronic Illness

A Presentation to the Family Symposium: Developing a Research and Demonstration Agenda

National Institute of Mental Health

November 23, 1992

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Methods of Knowing

(Design)

1. Personal descriptive accounts
2. Clinical reports of providers
3. Cross-sectional studies with clinical samples
4. Experimental intervention

Levels of Family Measurement

I. Demographic
   Family Structure

II. Individual family member about the family
   a. from one member
   b. 2 or more members
      Combined -- Relational

III. Family Interaction
   a. observer code
   b. behavioral product score from interaction

Family Constructs

Structure

Stress and Coping

Social Support

Family Interaction Patterns
- cohesion
- communication
- flexibility

Family Functioning Style
- balanced
- centripetal -- centrifugal

What Research is Needed

Epidemiologic -- Prevalence

Theory-based -- Especially family systems

Multiple units of analysis

Multiple methods/informants

Better sampling

Qualitative and quantitative

Resiliency studies

Intervention Studies

- Treatment development
- Timing of intervention
- Unit of intervention
- Prevention

Process studies

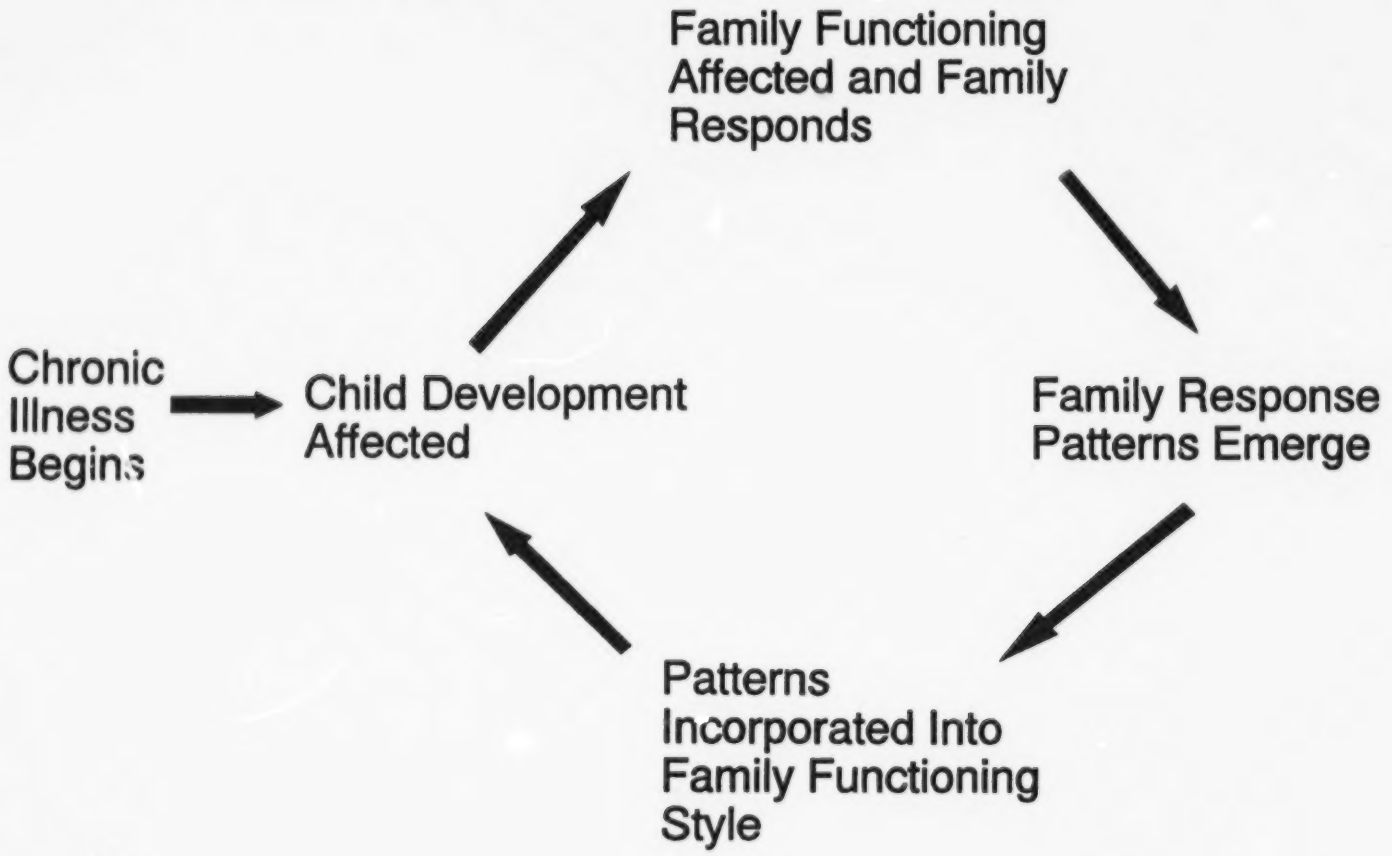
- natural family process
- family-provider interaction

Trends in Family and Chronic Illness Research

Problem-focused	→	Adaptation focused
Univariate	→	Multivariate
Single method	→	Multimethod
Single informant	→	Multiple informants
Outcome	→	and Process
Structural variables	→	Process variables
Linear	→	Systemic
Cultural homogeneity	→	Diversity Heterogeneity

B6

Relationship of Child's Disability to Child Development and Family Functioning


Family Functioning Affected and Family Responds
Chronic Illness Begins
Child Development Affected
Family Response Patterns Emerge
Patterns Incorporated Into Family Functioning Style

Recent Trends in Research on Families of Persons with Developmental Disabilities

A presentation to the Family Symposium: Developing a Research and Demonstration Agenda

National Institute of Mental Health
November 23, 1992

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ABSTRACT: Research Trends: Families of Children with Developmental Disabilities

The field of research on families of persons with developmental disabilities has experienced extensive growth in the past decade. Recent studies reflect a more complex view of families and an appreciation for adaptive as well as maladaptive family processes. The research has been influenced by important public policy trends including the emphasis on families in early intervention, the central importance of community living as a long term outcome for persons with disability, the growth of a strong family advocacy movement, and the creation of family support services in several states. In addition the research in this area has reflected broader trends in the social sciences including interest in resilience and positive adaptation, the interactions of cognitive and environmental variables, and attention to social support networks and community services as influences on family systems. Recent treatment research has begun to target parental and sibling stress and distress for amelioration and prevention. Some implications of this body of work for research on families of children with emotional disabilities are discussed.

RESEARCH TRENDS: Families of Children with Developmental Disabilities

1. **Recognition of the centrality of the family system for child outcomes**

   a. family influence on adaptive behavior
   b. concern for parents and siblings as recipients of intervention
   c. acknowledgement of the long term role of families for community integration.

2. **Recognition of positive adaptation as a common outcome.**

   a. renewed interest in parental accounts
   b. rejection of family pathology model
   c. development of measures of positive adaptation to disability
   d. study of effective families.

3. **Development of multivariate, contextual models**

   a. greater specificity of stressors
   b. addition of cognitive variables
   c. attention to family social context
   d. attention to community resources

4. **Expansion of applied behavioral research into larger social context.**

   a. family generalization
   b. setting generalization
   c. need for adjunctive treatments to enhance maintenance
   d. attention to antecedents of problem behavior-communicative interventions.

5. **Increased attention to life span studies.**

   a. recognition of long term importance of families
   b. response to changing demographics
   c. concern with transitions from school to work

d. attention to elderly caregiver.

6. **Focus on parent/professional relationships.**

a. research on impact of self-help organizations
b. interventions to improve interactions
c. identification of effective professional practices
d. training of parents to cope with professional

APPENDIX C

FAMILY RESEARCH THEMES AND TOPICS

Following is a list of all topics and themes generated by symposium participants in work sessions and individual worksheets.

- Impact of racism and discrimination on minority families
- Overall community context of child development, including the African notion that it takes a village to raise a child
- Impact of new research knowledge on training
- Effectiveness of community-based service regarding broad population of children
- Early intervention
- Managing inequalities in the child mental health system
- Shift from moral advocacy alone to moral advocacy plus a research knowledge base to influence public policy
- Linkage of neuro-biological research knowledge to service development
- Development of outcome measures and concepts that reflect CASSP values
- Financing
- Service effectiveness
- Interventions on behalf of caregivers
- Family competence and family empowerment
- Sensitivity of research to community context and environment
- Cultural competence
- Shifting research and demonstration focus from an individual orientation to a family orientation
- Barriers that families experience in gaining access to services
- Cross-cultural studies
- Contributions from other fields such as developmental disabilities
- Use of concepts pejorative to families, e.g., "Double bind", "Deviance"
- Blaming families and traditional reliance on deficit models & assessments
- Emphasis on "family burden"

- Move towards family education
- Shift in units of analysis, child & family systems
- Focus on white middle class mothers
- Use of "dysfunctional" terminology
- Move towards psychoeducational models
- Lack of attention to child's/families' needs
- Rise of consumer movements and self-advocates
- Lack of focus of research on interventions, particularly institutionalization, service delivery options, development of community-based options
- Fragmentation of research & service delivery; fragmented theories; lack of interagency coordination; lack of parity in systems of care
- Questions as to who is the "informant" in research: therapist, family member, family unit?
- Lack of communication between mental health and education systems
- The different roles of quantitative and qualitative methodologies
- The lack of attention paid by diagnostic approaches to developmental issues
- Studies of how families develop
- Studies on biculturalism or multicultural competence
- Studies on innovative multicultural interventions
- Inter-disciplinary research including psychiatry
- Development of DSM-4
- Cost analysis studies that look at societal benefit as well as individual benefit
- Better understanding of abuse and neglect and the related issue of blame
- Qualitative research to learn more about how families define "quality of life" and "competence" in children
- Systematic study of the values of all stakeholders
- Families participation in measurement development efforts
- Measurement of system change
- Studies of what makes a child successful

- Studies of what factors determine various children's pathways into different systems, i.e., juvenile justice, mental health, child welfare, etc.
- Descriptive studies of coping strategies for families and their children living in poverty and families of color
- Studies of families within the context of the communities and systems in which they live (including natural helping context of community)
- View that consumers and stakeholders are equally important in framing interventions and formulating research
- Cross-cutting issues across disability and diagnosis with regard to family support
- Fragmentation of the service system
- Impact of researchers' and evaluators' values in defining family needs and priorities as well as interactions with families
- More implementation studies of innovative intervention approaches
- Relationships of communities to families -- community ownership of kids, programs, etc.
- Child rearing practice in various families
- Caregiving families with special needs: (families with AIDS, adoptive families, substance abuse)
- Research on abuse and neglect
- Transition services at early adulthood
- Parent to parent support, example: "warm lines"
- Research on other services besides therapy, e.g., respite, psycho-education, prevention
- Support for professionals, since many who serve families according to CASSP principles do not receive much support from their agencies or professional organizations
- Issues pertaining to national health insurance
- Family involvement in training professionals
- Consumer movement influencing service providers and researchers
- Integration of specialization (vs. fragmentation) - lots of experts have dealt in isolation with same population
- Studies of the quality of families' lives
- Multi-disciplinary research using different methods

- Influence of values on research process - need for systematic study of this issue
- Research on school system, child welfare, mental health, judicial -- with as much rigor as we study family systems
- Use of informal versus formal services by families
- Why kids end up in juvenile justice and mental health system
- Emphasis on "maximizing potential" versus "management and control"
- Coping strategies of families who live with violence and poverty - sift out mental health versus social economic issues
- Need for descriptive studies
- Research on how to do research - how to sensitize researchers so they can access families to be studied - we've thought they are not accessible but in fact they're willing/eager to be involved - they know what to tell us - we don't know how to ask it
- Use of research knowledge to inform/influence curricula of schools training professionals
- Study of racism as DSM-III category (parallel to a delusional disorder)
- How to better provide services to populations that do not access existing services
- Custody issue - why do families give up custody?
- Diagnostic system for kid's disorders
- Difference between a label and a diagnosis
- Study of outcomes - clinical/researcher, consumer, societal (ex. cost effectiveness) cost vs. benefit
- Develop capacity to build systems with states that do not have them
- Monitoring - families need to be part of assessing effectiveness
- Building parent-professional collaboration in services and research
- Practice of "coercive" family therapy as a condition for services
- Physical attributes and health status of caregiving families (obesity, high blood pressure, self-medicating, etc.) and how interventions affect those attributes
- Involvement of families in conceptualizing and designing programs
- The effectiveness of "family support movement" on services
- Financing of community-based, family-centered, flexible services/supports
- Cultural competence - how families/kids develop bicultural competence

OTHER RESEARCH ISSUES GLEANED FROM PARTICIPANTS' WORKSHEETS:

- Research about what types of interventions help youth to function successfully in school and in the community
- Need to design interventions in light of accurate diagnoses. If we don't have this, how can appropriate service systems be designed?
- Research regarding the quality of life of families who live with a child or adolescent with various disorders/mental illnesses
- What are the effects of intensive supportive services for families?
- What has been the course of illness for children? What were early behaviors of child, what was early diagnosis compared with later diagnosis?
- What are effective ways to prepare educational systems to work with the more seriously mentally ill children?
- What is the incidence and prevalence of families' having to give up legal custody of their children to gain access to services?
- What can be done to prevent families' having to give up custody?
- What happens to children who leave residential treatment and return to community services? Need studies to take into account variety of circumstances, i.e., return to own families, with and without supportive services, return to community transitional facilities, etc.
- For what children under what circumstances do intensive wrap-around services work? Especially concerned about children with severe (neurobiological) problems. Need to compare outcomes across variety of circumstances (at home, in residential treatment, varied support and severity).

APPENDIX D

McGonigel, M. (1988). *Guidelines for family-centered research.* Association for the Care of Children's Health: Washington, D.C.

Patterson, J.M. (1990). Family and health research in the 1980's: A family scientist's perspective. *Family Systems Medicine,* 8(4), 421-434.

Patterson, J.M. (1988). Chronic illness in children and the impact on families. In C. Chilman, E. Nunnally & F. Cox (eds.), *Chronic Illness and Disability.* Beverly Hills, CA: Sage, 1988, pp. 69-115.

Singer, G.H.S. & Irvin, L.K. (1990). Supporting families of persons with severe disabilities: Emerging finding, practices, and questions. In L.H. Meyer, C.A. Peck, and L. Brown (Eds.), *Critical Issues in the Lives of People with Severe Disabilities.* Baltimore: Paul H. Brookes, pp. 271-312.

Turnbull, H.R., and Turnbull, A.P. (1980). *Report of consensus conference on principles of family research.* Beach Center on Families and Disability: Lawrence, Kansas.

Journals relevant to family research:

Journal of Child and Family Studies
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Journal of Emotional and Behavioral Disorders
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Journal of Emotional and Behavioral Problems
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Family Research and Demonstration Symposium Report

EVALUATION FORM

1. Who used the report? (Check all that apply.)

   ___Parent ___Educator ___Child Welfare Worker

   ___Juvenile Justice Worker ___Mental Health Professional

   Other (Please Specify)_____

2. Please describe the purpose(s) for which you used the report:

   _____

   _____

3. Would you recommend use of the report to others? (Circle one)

   Definitely Maybe Conditionally Under No Circumstances

   Comments:_____

4. Overall, I thought the report was: (Circle one)

   Excellent Average Poor

   Comments:_____

5. Please offer suggestions for the improvement of subsequent editions of this report:

   _____

   _____

   _____

   _____

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

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